



Breaking Ground

It Takes a Community to Raise a Child

By Shirley Lewis Burr

"It takes a community to raise a child" is an old proverb, but it truly depicts the life of a contemporary young man from East Tennessee.

His name is Jason Michael Lewis. He was born in July, 1983, and in his first few years he did not develop in most ways appropriate to his age. He was "slow" in speech and language, and only repeated things he heard. He moved both hands opposite one another, made no eye contact, was reluctant to be touched, and did not pretend play. At age three, he had a grand mal seizure, resulting in brain damage in the right frontal lobe. Later, it was learned that he had been having up to 100 petite mal seizures each day.

That was the only history I had of Jason when he entered my home at age three-and-a-half, still in diapers and on a bottle, and totally dependent on a caregiver. He was withdrawn, showed no emotion, never cried, exhibited no feelings of pain even from his self-mutilation of his hands. I took on this challenge knowing it could become a lifelong commitment for his care.

After many tests and evaluations, Jason was first diagnosed with severe mental retardation, then with autism, having 14 of 19 telling symptoms. Autism is a lifelong neurological developmental disability, and may be incapacitating.

He also had sensory integration disorder, auditory processing disorder, symbolic dyslexia, developmental, social, learning, and speech delays, attention deficit / hyperactivity disorder, and numerous chemical and food allergies. The food allergies included dairy products and water. The chemical allergies were actually harder to deal with, since they prevented him from taking many needed medications.

A different dream

Jason seemingly had a hopeless beginning in life. I felt inadequate because I

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Jason Lewis
in his ROTC
uniform.

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did not know what to do. The constant care, lack of sleep, decisions that had to be made with inadequate knowledge, endless trips to doctors, hospitals, therapists, and evaluators—all drained my personal life and made me doubt my sanity and ability to care for this child. All parents have a dream about their children. When a child has a disability, sometimes that dream has to be different. My dream for Jason was that he become independent and somehow overcome these difficulties.

Reading about his many disabilities and going to conferences, seminars, and workshops made me realize that there was help for my child and me. I learned how to teach Jason self-worth, motivation skills, reasoning capabilities, learning techniques, communication, socialization, interpersonal skills, and how to turn negatives into positives. I set goals for helping this child become socially acceptable, control or redirect compulsions, and attain skills that would enable him to live independently.

But goals are of no value if they are not sought on a daily basis by all involved. That includes parents, teachers, therapists, doctors, evaluators, the community and so many more.

So how did my community help raise this child?

His educational program focused on improving communication, social, academic, behavioral, and daily living skills within a classroom environment where information was presented both verbally and visually. Peer Buddies (fellow students) were assigned for each class to help him. When he progressed out of special education and resource classes into regular classes, an adult aide was hired to accompany him during the school day. There were numerous

others involved, including speech therapists, audiologists, medical specialists, mediators, advocates, support organizations, psychologists, psychiatrists, and more. Walter Ring, a psychologist, said of his work with Jason, “I felt unprepared and overwhelmed to take him as a client but agreed to because Jason’s mother convinced me that services were needed now and in her hometown. It has been a humbling and powerful experience to work with Jason, and my life has been enriched by my contact with him.”

When Jason was four years old, he entered the school system. His first teacher, Connie Hartzell, remembers him indulging his love for shoes by wearing bright blue canvas ones, pointy toe boots, or vividly colored sneakers. His first step toward mainstreaming was second grade math class.

Determined to succeed

Other teachers in elementary school were amazed at how hard Jason worked. They also noticed his influence on his fellow students. In sixth grade, Jason competed in a spelling bee against sixth, seventh, and eighth graders. When the contest ended, he had attained fifth place.

In a science class, he was chosen as one of seven students to be included in a special Marsville project because the teacher, Mr. Ray Fugate, felt Jason had made tremendous strides. The students constructed a mock colony on Mars, in competition with other schools in the region. One of the challenges was to put together nutritious meals for the crew utilizing limited space. Jason figured out how to place meals in a specified size and weight container when no one else had been able to. Mr. Fugate later remarked, “Through my experience with Jason, I learned not to pre-judge how a student will perform in a class. That helped me in my experiences as an educator and now school principal.”

Music is a natural talent with Jason, so he took piano lessons for three years and flute lessons for a year. He was in the elementary school marching band and high school concert band. He both reads music and plays by ear.



Jason receives his diploma at Rhea County High School in May 2001.

Once a week he attended AWANA, a Bible club that focuses on memorizing scriptural verses and offers rewards through uniforms, patches, and pins. 4-H gave him opportunities for competition, such as public speaking in which he won first place at his school and fifth in county competition with a speech entitled, "What It Is Like To Be Me."



Jason taking a break from a Scouting activity.

An active life

Jason became interested in NASCAR and wanted to drive a race car. He has met several drivers and was allowed to sit in the seat of one of their cars and start the engine. An article about him appeared in *Mr. Goodwrench* magazine, written by Dale Dorman, show car driver.

The local Boy Scout troop was reluctant at first to accept Jason, but they rose to the challenge. He has been in Scouts for more than six years. Marvin Denton, a Scouting leader, says, "I think Scouting has benefited from Jason being in it, and he has benefited from these experiences."

Summer camps have also been part of his life. From the age of eight, he attended epilepsy camps. Melinda Hickey, the camping director, says, "We have seen Jason grow into a young man and are proud to have been part of it. He was a shy, quiet child at first, but now he steps forward to reassure new campers about how much fun they're going to have. The younger kids look up to him in more ways than one."

On Sundays we attend church, and Jason has been part of the youth program for several years. The Reverend Milton Knox notes that "the young people have accepted Jason and treated him like any other member of the group."

Jason holds a volunteer job for two or three hours in the afternoons, made possible by the School to Work program of his school. Gary Dunn, director of the agency, says, "I found Jason capable of mastering many types of job skills with a genuine desire to do his job correctly and taking pride in doing it well. He has been a blessing in my education about life and the limitless possibilities that it holds."

Katrina Casteel remembers Jason at age four, when she was his teacher and he was a bewildered child trying to understand his new environment. She has been involved in his educational journey as Rhea County Special Education Supervisor after teaching him that first year. "Times were not always easy for him, parents, or school personnel," she says. "But he has become the first student with autism to complete academic work in most regular classes. He passed the high school proficiency exam and met all the requirements to receive, not a special education but a regular diploma."

At graduation awards day last spring, Jason received an award for outstanding achievement in special programs. He is entering college this fall with hopes to pursue an architectural engineering degree. There are still many obstacles of communication, socialization, information processing for decision making, and inconsistency that need continued work by all.

From a seemingly hopeless beginning, Jason Lewis has accomplished and overcome so much. I owe it all to the team of people that had enough faith in my son and me. I encourage parents and caregivers of children with disabilities to reach out to their own community and work together. My experience has truly shown me that a community can raise a child. ■

*Shirley Lewis Burr
and her family live in
Dayton, Tennessee.*

Consumers Offer Input on Services for People with Mental Retardation

By Walter Rogers

In an effort to improve services for individuals with mental retardation, state officials and The Arc of Tennessee scheduled a series of seven meetings with consumers across the state. “We are working hard to improve our program for individuals with mental retardation in Tennessee,” said Joanna Damons, director of the TennCare Division of Long-Term Care, which is responsible for the administrative oversight of the Home- and Community-Based Services Waiver for individuals with mental retardation.

The hope was to come away from these meetings with some solutions to problems identified by the Centers for Medicaid/Medicare Services (CMS), formerly known as the Health Care Financing Administration (HCFA). Earlier this year CMS performed an audit of services provided for people with mental retardation in our state. As a result of the audit, the TennCare Division of Long-Term Care would like to make sure that people with mental retardation and their families know that they are responsible for

the waiver program in Tennessee. This means that TennCare must assure the health, safety and welfare of all waiver enrollees. TennCare contracts with the Division of Mental Retardation Services for the day-to-day operation of the waiver. However, TennCare is always available to hear concerns or provide information that may help people and their families to understand the waiver program better.

The primary purpose for meeting with people and their families was to find out what was working and what was not working in the current system. Throughout the state, the majority of the participants were families of people using waiver-funded services or on the waiting list for the services. Many were frustrated and offered suggestions for reform. Concerns reported in the CMS audit were echoed by many of the people attending these meetings across the state.

A ‘system’ in shambles. Parents reported not knowing where to find state services for their children, being discouraged from applying for services and being told that there were long waiting lists or that only people who “bug them to death or get congressmen to write on their behalf” were getting responses. Many families cited a confusing system in which people complete an application, thinking they’ll be put on a waiting list for services only to find out a year or two later they didn’t know about all the necessary paperwork and still aren’t on a list. Others reported finding out their applications had never been filed to put them on the waiting list in the first place.

Other suggestions were for a single toll-free number that parents could call to find out what services are available and how to apply for them, and a state ombudsman to whom parents could



Walter Rogers, standing, Executive Director of The Arc of Tennessee, facilitates a TennCare Town Hall meeting in Nashville.



The Pathfinder web site is a one-stop Internet “gateway” to services and resources in Tennessee and to national resources, including Spanish sites.

Pathfinder topics include:

Advocacy
Assistive Technology
Child Care
Education
Employment
Family Support
Health Care
Houses of Worship (*changing to Communities of Faith*)
Housing
Independent Living
Information & Referral
Library
Mental Health
News
Post Office
Recreation
Respite Services
Tennessee Disability Services (*by Jan. 2002, you will be able to search by county and type of service in a database of 1400 Tennessee disability service providers*)
Training
Transportation

Pathfinder was developed as an activity of a Family Support Model Demonstration Project funded by a grant from the Administration on Developmental Disabilities to the Tennessee Council on Developmental Disabilities, in partnership with Vanderbilt University’s John F. Kennedy Center for Research on Human Development and IAM CARES.

We encourage individuals to “bookmark” this site for quick access, and ask agencies to add a link to Pathfinder from their web sites.

We are continuing to improve this site and welcome your suggestions. Email jan.rosemergy@vanderbilt.edu or call (615) 322-8240. ■

speak directly or a family mentor who could help families work through the maze of getting supports. Families also suggested an entity independent of the state to which people could report abuse or neglect by service providers without fear of retaliation. Meeting participants also recommended the provision of school staff regarding services and the Medicaid Waiver, as well as transition planning. They also felt that there needed to be an “automatic” referral and transfer of information to the Division of Mental Retardation Services from the Department of Education.

In many meetings families and their sons or daughters felt that the turnover of direct care staff was too high. They recommended that a certification/training program and increased wages paid address this issue.

Family response to the Independent Support Coordinator (ISC) system was mixed across the state. Some families felt that it was not working and recommended more training for the ISC’s and decreasing paper work requirements so that they could spend more time with the persons they are supporting. Others felt that their ISC was very supportive and assisted them greatly in securing supports for their family member. On a related topic, the meeting participants felt that the Individual Support Plans were too long and that direct support staff were not reading them.

Joanna Damons stated that many of the complaints were no surprise and that the suggested solutions would be considered carefully. Said Ms. Damons, “I am really grateful people are willing to take the time to come and tell us what will help them. I learned a lot from these meetings.” ■

Tennessee Council on Developmental Disabilities

Five-Year Plan (2001 - 2006)

State Service System and Trends

Part of the Five-Year Plan developed by the Council on Developmental Disabilities includes descriptions of factors and issues that affect Tennesseans with developmental disabilities, the status of State service systems, and a review of waiting lists in the state. Presented below are highlights of the Five-Year Plan, which was submitted to the Administration on Developmental Disabilities in August 2001. The full text is available from the Council.

Environmental Factors Affecting Services

Waiting Lists

Waiting lists for residential, day and employment services and supports, as well as for Family Support, continue to grow. Some 3,096 individuals are on the Family Support Program waiting list, despite budget increases for the past two years. As of May 31, 2001, the Division of Mental Retardation Services (DMRS) has an additional 2,314 individuals on a waiting list for residential, day, and employment services. These individuals include aging individuals with mental retardation and developmental disabilities, students making the transition from special education programs and ready for the workforce, and children from birth to age three who need early intervention services. The Arc of Tennessee estimates that the waiting list will grow by at least 1,000 individuals per year and has presented a bill to the Tennessee General Assembly to provide supports and services to 5,000 individuals by the year 2005. The General Assembly established a study committee to research the waiting list issue and prepare a

report for legislators. The study committee presented its recommendations on November 1, 2000. DMRS has been charged with developing an implementation plan. Tennessee Protection & Advocacy, Inc. (TP&A) has sued the State on behalf of six plaintiffs who have been on the waiting list since 1995.

OPTIONS is a new program begun January 2001 for individuals who are elderly or disabled, but it is funded at only \$5 million. Under the Older Americans Act Program, 3,694 are on a waiting list for homemaker services, and 1,563 for home-delivered meals.

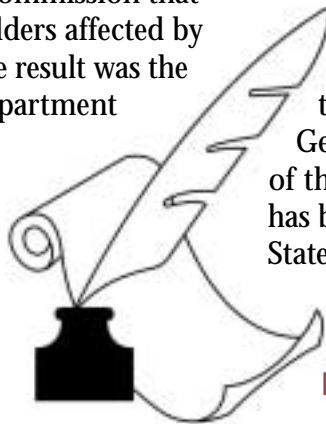
Long-Term Care

Currently, there is minimal home- and community-based long-term care available for individuals with disabilities in Tennessee. A Long-Term Care Planning Council and Long-Term Care Advisory Council met throughout 1998 to prepare a waiver plan to present to the Health Care Financing Administration (HCFA) to remedy this situation. A plan was submitted to the Governor in March 1999. The plan includes specified services and an individual cap. These long-term care services would be available to Medicaid-eligible individuals who are also eligible for nursing homes. To date, this waiver has not been submitted, and funding for it from last year has been lost. \$5 million dollars in unmatched State dollars fund a program of homemaker services and meals on wheels for non-Medicaid-eligible individuals who are elderly or have physical disabilities. Even with this program, Tennessee is ranked 50th in the nation for provision of home and community based long-term care.

An improvement budget for the non-Medicaid-eligible program (OPTIONS, which began January 1, 2001) was not included in the recent bare-bones budget passed by the General Assembly. Ten million dollars were approved for the Medicaid-eligible waiver (which has not yet been submitted to the Centers for Medicare and Medicaid Services) but the funds may have to be used to repay federal funding due to a nursing home fund dispute.

Department of Mental Retardation and Developmental Disabilities

The General Assembly recently passed legislation revising the statute that established the Department of Mental Health and Mental Retardation. This legislation was based on the work of the Title 33 Revision Commission that solicited input from all stakeholders affected by the statute. A significant positive result was the changing of the name of the department to the Department of Mental Health and Developmental Disabilities (DMH/DD). The new law expands the definition of eligibility to receive services, especially for employment and housing, to include Tennesseans with developmental disabilities based on the federal definition. Previously, only individuals with mental retardation or autism were eligible to receive such services. The bill provides for one year of study to prepare for the broadened eligibility. New eligibility definitions become effective in March 2002. The legislation also provides for citizen-based planning and policy development to advise the Department about maintenance and improvement of the service systems and to tie plans to the Department's budget requests. The DMH/DD received some improvement requests and DMRS received all improvement requests for FY2002. Despite these gains, Tennessee Housing Development Authority funds have been permanently lost for grants to non-profits to provide rental housing for individuals with cognitive disabilities.



Inclusion of Students with Disabilities in General Classrooms

Many parents, advocates, teachers and administrators agree that the Individuals with Disabilities Education Act (IDEA) is not being implemented in a consistent manner statewide. Although there are a number of individual school systems that include students with disabilities in general classrooms, many school systems still have segregated classrooms for students in special education. The State does monitor school systems for compliance with IDEA. A new law requires the Department of Education to develop case load requirements and standards addressing class size in all classrooms that include students with disabilities and students eligible for special education services, by February 1, 2002, such standards to take effect for the 2002-2003 school year. However, implementation of this bill is subject to funding in the General Appropriations Act. Organization of the Disability Coalition on Education (DCE) has been effective in raising awareness at the State Board of Education.

The State Service System(s):

Interagency Initiatives

State departments have been improving coordination.

- Special Education is updating the interagency agreement between the Department of Education and DMH/DD to be more comprehensive and involve more parties, including Health and Children's Services.
- Department of Human Services (DHS) is negotiating Memoranda of Understanding with Department of Labor and Workforce Development and Local Workforce Investment Boards to include a full-time Vocational Rehabilitation (VR) counselor at 13 Career Centers for individuals with disabilities.
- DMH/DD has initiatives with TennCare Partners Program, Bureau of Alcohol and Drug Abuse Services, Commissioner's Task Force on Early and Periodic Screening, Diagnosis and

Treatment (EPSDT) and Substance Abuse and Mental Health Services Administration (SAMHSA) Child Mental Health Initiative Systems of Care.

- Department of Health, (DOH) is collaborating with DHS and Council on Developmental Disabilities to fund regional child care resource centers targeting inclusion of children with disabilities.
- Childrens Special Services is developing a statewide agreement with Tennessee Early Intervention System, the Department of Mental Health and Developmental Disabilities, the Division of Mental Retardation, the Division of Vocational Rehabilitation, Head Start, Tenn Care and Special Education for services to children from birth through age 3.
- Vocational Education plans to update and revise agreement with special education and VR.
- Tennessee Protection & Advocacy, Inc. has numerous coalitions and collaborations. These include (1) Disability Coalition on Education (DCE), (2) Advisory Committee for State Board of Education on new due process system, (3) interagency police training to educate about developmental disabilities and mental illness, (4) attorney training in special education and Americans with Disabilities Act (ADA) to increase pro bono services with Tennessee Bar Association and Legal Services, and (5) advisory councils in two major schools systems to improve special education supports and services.
- Department of Labor and Workforce Development has State and local Boards comprised of several private and DHS, VR representatives.

Stakeholder Input

There has been an increase in participation from individuals with disabilities and family members on policy, procedures, rules and regulations.

- Special Education developed an Implementation Plan after reauthorization of IDEA and developed rules and regulations.
- State Board of Education is reviewing the Implementation Plan with substantive

input from parents and advocates.

- DMH/DD mental health and substance abuse services are being provided under managed care umbrella of TennCare Partners Program, and program directors meet regularly with Partners Monitoring Group advocates.
- DOH's Traumatic Brain Injury (TBI) Program collaborates with Education and Tennessee Disability Coalition in a federal grant project to provide training to school personnel working with students with TBI.
- DMRS conducts multiple work groups, task forces and policy committees that involve other state agencies, providers, individuals with developmental disabilities and their families.

Housing

Several continuing and new initiatives for housing choices for individuals with disabilities are underway.

- DMH/DD has begun a statewide program to develop housing choices for individuals with mental illness.
- Tennessee Housing Development Agency collaborates with DMRS on STRAP to provide assistance with rent for individuals leaving developmental centers and moving into the community.
- DMRS collaborates with the CDD home ownership project and provides funds to assist with down payments for individuals moving into the community from developmental centers.

Employment

New initiatives are underway towards the employment of individuals with disabilities.

- DHS is expanding job placement services for Vocational Rehabilitation and Blind Services, is forming Business Leadership Networks in the seven regions of the state, and is placing a full time VR counselor at each of 13 Career Centers for individuals with disabilities. It also has a Case Manager program at each of the four Developmental Centers to address vocational needs of individuals transitioning to community based employment.
- Vocational Education says equal access to a full

Council Welcomes a New Staffer



Margaret Donald

Anyone who has called the Council office recently may wonder to whom the friendly new voice on the telephone belongs. The Council is pleased to welcome Margaret Donald as Administrative Secretary.

Margaret is originally from West Tennessee and worked for the Arlington Developmental Center as Team Secretary for the Maple 2 and Maple 3 Homes. She has worked also as a house manager for eight ladies with developmental delays. Margaret remains very close to these women.

Margaret is the mother of two sons. Larry lives in Toledo, Ohio, with his wife, Trevia, and daughter, Israel. Brian is in the U.S. Navy and is stationed in Norfolk, Virginia. Margaret does quite a bit of traveling. In her spare time, she enjoys reading, especially Walter Mosley, John Grisham and historical novels about the Renaissance era. ■

- range of vocational education programs is provided via recruitment, enrollment and placement activities for members of special populations. However, involvement with a major school system indicates that there needs to be more communication between special education and vocational education personnel and that vocational education teachers need training on working with students with disabilities.
- The new Department of Labor and Workforce Development wants to create a service delivery system that is seamless, unified and is responsive to the needs of each individual needing services offered in all of the career centers established in each local investment area of the state. The Department says the intent is to increase services to persons with disabilities through a referral process that will be created at the local level.

Olmstead Decision

Tennessee currently does not have a comprehensive Olmstead Implementation plan. There are many splintered activities related to Olmstead but the state should have a unified, comprehensive planning document to make sure all departments are moving in the same directions. To this end, the Council on Developmental Disabilities has taken a leadership role in the formation of the Tennessee Olmstead Coalition (TOC). TOC is a grassroots group of Tennessee disability service

system stakeholders who have united to provide leadership, direction and oversight to the development and implementation of Tennessee's Olmstead Plan. The leaders of the Tennessee Olmstead Coalition are people with disabilities who have a personal stake in assuring Tennessee's service delivery system serves and supports people in the most integrated setting appropriate to meet their needs. All members of the TOC have made a pledge of specific organizational and personal resources in order to birth this Coalition.

Changing service population

Tennessee is seeing some changes in the prevalence of some developmental disabilities. For example, between 1998 and 2000, there has been an increase of 229 children with the label of autism in the Tennessee school system and a decrease of 665 students with the label of mental retardation. Similarly, the Family Support Program saw the percentage of individuals with autism served increase from 5.5% to 6.9% between 1995 and 2000. In the same period, the percentage of individuals with multiple disabilities served increased from 21.9% to 27.3%.

The same fiscal issue affects virtually the entire state service system for Tennesseans with disabilities. The state is totally dependent on sales tax revenue; tax reform failed in last three legislative sessions. ■

Tennessee Disability

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For individuals with disabilities, family members, and agency staff, finding information and specific services in a community is often difficult and time-consuming. The Tennessee Disability Information and Referral (TDIR) Office is “a good place to start” when seeking current information about disability resources around the state. The scope of information includes all disabilities and individuals of all ages. The office can be contacted by phone or e-mail.

The most requested services include: Housing, Financial Assistance, Social Security Disability Income, and Employment or Job Training. Community resources are sometimes limited, but there are outstanding programs and individuals working to expand and improve services for individuals with disabilities around Tennessee.

New Disability Service Directories

The 2001/2002 Disability Services and Supports Directory published by the Tennessee Disability Information & Referral Office will be available for distribution in December. This statewide directory is published in three volumes, East, Middle, and West editions. In addition to a listing of services available in each county, the directory includes updated articles on Americans with Disabilities Act (ADA), Family Support Program, Housing Resources, Individuals with Disabilities Education Act (IDEA), National Disability Organizations, Social Security Disability (SSI & SSDI), TennCare, and list of Tennessee legislators.

A complimentary copy will be provided to each agency listed in the directory and to Tennessee libraries. Directories can be purchased. Each regional directory costs \$40, or all three cost \$80, plus \$5 postage. See contact information at end of this article to order. An order form is also available on the I&R web site.

TENNESSEE
DISABILITY
INFORMATION
AND REFERRAL
OFFICE



Telecommunications Devices Access Program (TDAP)

The Telecommunications Devices Access Program (TDAP) was established by the Tennessee General Assembly in 1999. TDAP is designed to distribute appropriate telecommunications devices so that persons who are severely hard of hearing and vision impaired, or severely speech impaired may effectively use basic telephone service.

Types of equipment available include: amplified telephone, uniphone, basic TTY and printer, large visual display TTY, and braille TTY. The devices are issued free of charge on a first-come basis; however, certain qualifiers may enable individuals to receive devices on a priority basis. For an application or further information, contact:

Patrice Barner

Tennessee Regulatory Authority

800-342-8359 Ext 179 or 206

615-741-2904 Ext 179 or 206

888-276-0677 (V/TTY)

www.state.tn.us/tra/consumerfiles/tdap.htm

Telecommunications Relay Service

The Telecommunications Relay Service is a managed Tennessee Regulatory Authority contracted service that provides a Communications Assistant (CA) to translate conversation between a telephone user and a TTY/TDD user. Here are the numbers to call:

TN TTY Access: 800-848-0298

TN Voice Access: 800-848-0299

TN Spanish: 866-503-0263

(voice, TTY, ASCII)

TN Speech-to-Speech: 866-503-0264

TN 900 Access: 900-476-2727 (TTY)

TN Customer Service: 866-503-0262

(voice, TTY, ASCII)

Information & Referral Office

By Carole Moore-Slater

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The Tennessee Regulatory Authority has a contract with MCI Global Relay to provide this service in Tennessee.

What is Speech-to-Speech Relay?

- Speech-to-Speech (STS) service enables a person with a speech disability to communicate on the telephone by using his or her own voice, voice synthesizer, or other assistive device by telephone.
- There is no charge to the STS user to access or use this service. STS calls are billed as if dialed directly without the STS relay service.
- STS customers can call a toll free number and reach a specially trained Communications Assistant (CA) who will provide assistance in completing an STS call. The two customers (one with a speech disability and one without) communicate directly with each other through the assistance of the CA.
- Available 7 days a week, 24 hours a day.
- There is no limit to the number of Speech-to-Speech relay calls a caller can make.

How does Speech-to-Speech Relay Work?

- Dial the Speech-to-Speech Relay number (listed above).
- You will reach a specially trained STS Communication Assistant (CA) who will announce the call as: "Speech-to-Speech Relay Service, may I have the number you are calling please?"
- Tell the CA the area code and telephone number you are calling, along with any calling instructions if needed.
- The CA will then ask you if you wish for the CA to play an active or passive role in the process of relaying your call. If you want the CA to take an active role, the CA will repeat everything that is voiced by the STS user. If you want the CA to take a passive role, the CA

will only intervene upon request from the STS user or called party.

Telephone Assistance Programs

To insure that telephone service is available and affordable for low-income telephone subscribers, the Tennessee Regulatory Authority established Link-up and Lifeline Telephone Assistance Programs.

- Link-up will pay half of the installation charges for new telephone service, to a maximum of \$30. To further reduce the initial cost to establish new telephone service, request your local telephone company to divide the balance of the installation charge over a period of months. You will not be required to pay a deposit when connecting service under Link-up.
- Lifeline will save telephone subscribers up to \$12 per month on the local service portion of the telephone bill. By selecting the lowest cost residential service plan offered by the local telephone company, Lifeline ensures an affordable monthly telephone bill.

The qualifications for Link-up and Lifeline are the same. You automatically qualify if you presently receive Supplemental Security Income (SSI), or if your total household gross monthly income is within their guidelines. ■

To contact TDIR

800-460-INFO (4636)
800-273-9595 (TTY)
615-322-8529 (Nashville area)
615-343-5737 (FAX)
carole.moore-slater@vanderbilt.edu
www.vanderbilt.edu/kennedy/tdirs.html

Carole Moore-Slater is coordinator of the Tennessee Disability Information & Referral Office, a project of the Tennessee Council on Developmental Disabilities located at the John F. Kennedy Center, Vanderbilt University, Nashville.

My Dream Became A Reality

My name is Rhonda Clark and I am originally from Green Bay, Wisconsin. After several trips to Music City I knew that Nashville was where I wanted to call "home." Upon graduating from the University of Wisconsin-Green Bay with a degree in Communication Processes with an emphasis in Public Relations and Music Promotion, I moved to Nashville in January 1996.

When I first moved to Nashville, I stayed with some friends for about two months until we were able to find a place that was affordable and wheelchair accessible as I have cerebral palsy (CP) and use a power wheelchair for mobility. As I found while looking for a place to live, most of the accessible places to rent were already taken. After two months of calling around looking at places, with the help of the Center for Independent Living of

Middle Tennessee, I was able to find a place where I lived for almost five years.

The place consisted of a total of seven private rooms with bathrooms, and we all had to share a kitchen and living room area. This also meant that we shared kitchen

Rhonda's quest for an accessible home of her own finally paid off.

appliances as well. This was a housing situation for seniors and people with disabilities who could take care of their own personal needs.

During the first month of living there, I found out about a homebuyers class that was being offered at the Woodbine Community Organization and I decided to check it out. After several weeks in the class, I saw that if I paid only the minimum amount on my college



debt, which amounted to \$7,000, I would never get it paid off with my income as it was at that time. So I dropped out of the class, but started to put \$5 a month in the bank and putting as much as I could toward my debt.

In mid-September 1996, I received a phone call from the executive director of United Cerebral Palsy of Middle Tennessee (UCPMT) asking if I would be interested in coming to work for them part-time. They had received a grant from the National UCP office in Washington, D.C. and UCPMT was the site chosen to host the national segments of StarFest, an entertainment fundraising event benefiting the programs and services of UCPA and its affiliates. I jumped at the chance because it was music-related, which would tie me into a lot of people in the music industry—and it was money to pay my bills.

With the job at UCPMT being part-time, I was able to continue to pursue my goal of obtaining a job in the music industry. In September 1998, I was listening to Dave Ramsey on the radio, and I heard Dave mention Financial Peace University. I called his office to see what it was all about. Well, the day I called I was enrolled. Financial Peace University is a 13-week course for anyone who is interested in learning how to pay off debt and how to budget and plan for the future. It was really tough for me to go to the classes at first because I had never lived on a budget before in my life! Upon finishing the course, my college debt was paid off. This was due in part, too, because I was hired as the receptionist/clerk at Country Music Television in December 1998.

Once my debt was paid, I started toying around with the idea of owning my home again. Living with six roommates wears on you after a while, and the neighborhood went way down, and the crime went up.



While I continued to save, I began working with Lisa Lethcoe, a real estate agent from Coldwell Banker Lakeside Realtors in Hendersonville, Tennessee. We both knew going in that it was going to be a long process of finding a safe, affordable, and accessible place for me to live.

The first place that we looked at was completely wheelchair accessible with the wheelchair ramp and nice wide-open areas, but there was an age requirement to live there. The individual had to be 55 or older, and I did not qualify.

Once we had looked at several condos together, Lisa would go and preview condos within my price range and other amenities that I wanted. If she found something that she thought I would like, she would call me and then pick me up in my van or I would make arrangements to have someone go with us due to the fact that there may be a few steps to get into the condo.

After a year of an exhaustive search on Lisa's part and continued saving on my part, we put a contract down on a condo that I truly fell in love with. Then the mortgage process began, but I was not comfortable with the payments. Lisa said she would ask another mortgage specialist with whom she had worked before if I had any other options because I really wanted this particular condo. She contacted Brad Denton,

a mortgage specialist for GMAC Mortgage in Hendersonville. Within two weeks, Brad was able to do a Federal Housing Administration loan contract for the condo that I wanted.

Lisa and Brad obviously had my best interest in mind. It is my understanding that I am the first person with a disability that Lisa had been able to take all the way through the home buying experience successfully. It was largely due to Lisa's dedication to her job and her clients; she never stopped working for me. In fact, the day she e-mailed me the listing for the place where I currently live was New Year's Day 2001.

Once I closed on the condo and a ramp was built by UCPMT, the bathroom area was remodeled, a shower was put in, and doorways were widened. I was able to move into my very first home. I am sure I will be able to call it home for many years.

I would hope that if there is anyone wondering whether owning your own home is a dream or reality, as you can see it was made a reality for me and it can be the same for you. If I can be of any support or assistance to anyone wanting to go through the home buying experience, please contact me. ■

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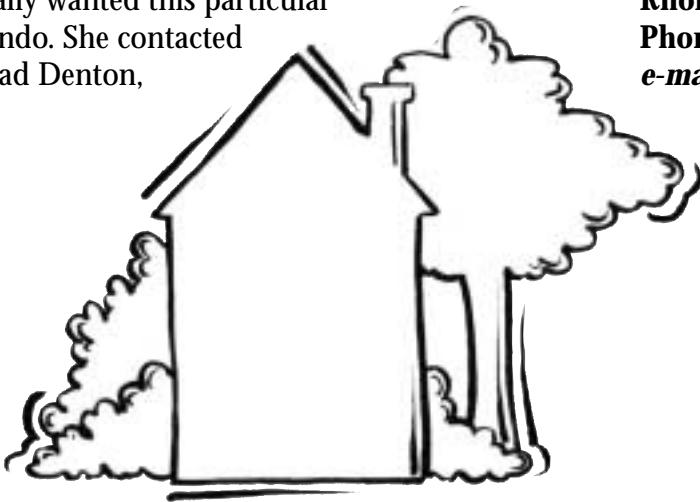
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Building A 'Universal Design' Home

By Jim Summerville

When Linda Climer, a Jackson builder and developer, decided to build an accessible house last year, she started with a trip to a bookstore.

"I had no plans," she recalls. "There wasn't another such home in town to go by. I went to Davis-Kidd Booksellers for a book on plumbing. That kind of research was how I got started."

"We found that some adaptations were actually better and easier to use by most people, whether or not they have a disability."

Ms. Climer also studied and observed the domestic needs of people with a disability. How does a kitchen need to be designed for an

individual who uses a wheelchair? What works in the bath to facilitate personal care?

"I had to find a contractor who could 'look outside the box,'" she says, and she did, in Joe Mitchell. She and he looked one by one at elements and details of the house and how each would be used. "We used a wheelchair to improvise spaces. And we found that some adaptations were actually better and easier to use by most people, whether or not they have a disability."

A home for everyone. That's why she calls the house a "universal design home." It's a place that anyone can live in, but it will yield itself to more adaptations as they may become needed.

For example, the chopping block in the kitchen is low, but it can be raised by changing out a drawer; likewise, with the lowered sink that can be raised.

"Joe would sometimes point out that a certain adaptation would work fine, but only for someone in a wheelchair. We'd then try to figure out a way to make it useful for everyone."

When you approach the property, located in the Cottonwood subdivision, you can't tell that the front door is ramped. Inside, there are no handrails around the walls—but there are blockings in the walls so they can be installed as needed. In her research, Ms. Climer spoke with people who had had to retrofit their houses to adapt to new physical conditions. To all the features she built in, others can be added easily.

"None of this came cheaply," Ms. Climer acknowledges. The best prospects for accessible homes may be people who own a home, but want to downsize. If as they age, they are faced with a disabling condition, they could remain in their universal design home.

Glen Barr, executive director of the Jackson Center for Independent Living, has helped with promoting the project in the community. "We had been working with the city for a few years, encouraging them to develop housing like this. In the end, it took one dedicated entrepreneur. We applaud Linda for her efforts in promoting independent living and homeownership for people with disabilities in Jackson." ■

*Jim Summerville
is editor of
Breaking Ground.*



Council Charts the Future

By Errol Elshtain

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The Tennessee Council on Developmental Disabilities had its annual Retreat at the end of September. This year, the Council invited members of its sister agencies under the Developmental Disabilities Assistance and Bill of Rights Act of 2000, Tennessee Protection & Advocacy, Inc., and the Boling Center for Developmental Disabilities. The purpose was to focus on potential areas of collaboration and ways to reach out to groups not usually connected to disability issues.

The first order of business was to review the accomplishments achieved by Council activities and grants for fiscal year 2000-2001, and to describe new initiatives underway in the current fiscal year (see the June 2001 issue of *Breaking Ground* for a description of the latter). This gives the Council an opportunity to examine which projects represent a strong investment and those that appear to produce a less significant return.

Wanda Willis, Executive Director of the Council, described the basic principles of the DD Act and noted that the three organizations created by the Act have a specific contribution to make toward the realization of the principles for individuals with disabilities and their families. This was followed by presentations from Shirley Shea, Executive Director of Tennessee Protection & Advocacy, Inc., and Frederick Palmer, M.D., Director of the Boling Center for Developmental Disabilities, about their respective organizations.

Raising awareness. During the summer, the three agencies comprising the DD Network collaborated to hold Listening Sessions with community representatives in Jackson, Knoxville, and Cookeville. The Council heard a report on the Listening Sessions from Cecilia Mynatt, of the Center for Nonprofit Management, who had facilitated the sessions. The idea was to gather together people who are not typically involved with disability advocacy or services, such as,

mayoral offices, city councils, school boards, chambers of commerce, realtors, banks, faith community, health care and public services. At least one individual with a disability and a family member were also invited. Three main topics were discussed: Level of Awareness about Disability Issues, Past and Current Experiences with Inclusion, and Opportunities to Include Persons with Disabilities in the Community.

The remainder of the Retreat involved small group discussions about effective collaboration and, specifically, areas in which the Tennessee DD Network could work together. Three topics highlighted were Needs Assessment, Public Awareness, and Identifying and Addressing Barriers to Inclusion.

Each group generated ideas for challenging and exciting potential projects, including joint brochures,

an annual statewide conference, a speaker's bureau, coordinated media contact, and tackling issues that affect individuals with disabilities across the state, like transportation, housing, and employment.

Everyone listened and worked hard during the day and a half of the Retreat. But that time generated increased understanding between the members of the Tennessee DD Network and a commitment toward working together to advance their similar visions and missions of individuals with disabilities being independent, productive, integrated, and included in their communities. ■

"To advance...the vision of individuals with disabilities being independent, productive, integrated and included in their communities."

*Errol Elshtain is
planning coordinator
for the Council
on Developmental
Disabilities.*

Tennessee Council on Developmental Disabilities

Five-Year Plan (2001 - 2006)

Goals and Objectives

When the Developmental Disabilities Assistance and Bill of Rights Act was reauthorized in October, 2000 (see article in *Breaking Ground*, Volume 10, Number Six, January 2001), the new Act replaced Priority Areas with Areas of Emphasis and called for a five-year plan instead of the previously required three-year plans.

The Goals and Objectives of the Tennessee Council on Developmental Disabilities Five-Year Plan submitted to the Administration on Developmental Disabilities in August 2001 and the rationales for the selection of Areas of Emphasis are presented below.

The rationale for goals related to advocacy, capacity building, and systemic change to be undertaken by the Council

Formal and Informal Community

Supports: For public awareness and advocacy, the Council supports the production of a legislative newsletter; a general newsletter; a made-for-television magazine program; an information and referral office; and an activity of a statewide self-advocacy organization.

Quality Assurance: To train individuals with disabilities and their families to be leaders in the promotion of systems change and capacity building; to encourage self-determination; to assess the quality of life of individuals who move from institutions into the community.

Employment: To emphasize systems change for agencies to direct human and financial resources toward supporting individuals in their

choices as they pursue inclusion in their communities, especially regarding employment; to foster development of corporate leaders and collaborative efforts among employers, state government agencies and community employment agencies toward increasing employment opportunities for individuals with disabilities.

Education: Many parents, advocates, teachers and administrators agree that the Individuals with Disabilities Education Act (IDEA) is not being implemented in a consistent manner. Although there are a number of individual school systems that include students with disabilities in general classrooms, many school systems still have segregated classrooms. The State does monitor school systems for compliance with IDEA. Tennessee is only beginning to develop student-teacher ratio to include students in special education.

Housing: To reduce the barriers to homeownership for individuals with disabilities so that owning a home is a viable choice.

Child Care: To provide support for inclusion of children with disabilities in regular settings.

FORMAL AND INFORMAL COMMUNITY SUPPORTS: Individuals have access to other services available or offered in a community, including formal and informal community supports that affect their quality of life.

Goal

To bring about specific and lasting change in

organizations, communities, and government to ensure full inclusion of individuals with disabilities.

Objectives

- By the end of FY2006, at least four State departments will include disability issues in planning efforts.
- By the end of FY2006, at least eight non-disability related organizations will increase their focus on issues and participation of individuals with disabilities.
- By the end of FY2003, the statewide information and referral services for persons with all types of disabilities will receive 20% more contacts.
- By the end of FY2006, educate and support at least five key policy and decision makers to support disability issues.
- By the end of FY2004, at least three communities will have parent teams affiliated with a medical university and a curriculum that incorporates all aspects and issues involved with the health care and education of children with chronic illness.

QUALITY ASSURANCE: People have the information, skills, opportunities, and support to live free of abuse, neglect, financial and sexual exploitation, and violation of their human and legal rights and the inappropriate use of restraints or seclusion. Quality assurance systems contribute to and protect self-determination, independence, productivity, and integration and inclusion in all facets of community life.

Goal

To develop and support leaders to promote systems change toward full inclusion and self-determination for individuals with disabilities.

Objectives

- By the end of FY2006, provide information, tools and support to empower at least

1400 individuals with disabilities or family members.

- By the end of FY2006, provide information on the quality of life of all individuals who have moved from developmental centers into the community and individuals still living in developmental centers.

FORMAL AND INFORMAL COMMUNITY SUPPORTS:

Individuals have access to other services available or offered in a community, including formal and informal community supports that affect their quality of life.

Goal

To increase public awareness about disability issues through coordinated and collaborative dissemination of information.

Objectives

- Publish two newsletters.
- By the end of FY2006, provide education about disabilities in at least four venues.
- By the end of FY 2002, present a photo exhibit of individuals with disabilities in their communities to at least six sites in Tennessee and two sites elsewhere.
- By the end of FY2003, distribute 4000 copies of a book of success stories of people who have moved from an institution into the community and are living meaningful lives.
- By the end of FY2004, at least 90,000 households in Tennessee will view television programming that portrays the lives of people with disabilities and provides an understanding of their independence goals and issues.

EMPLOYMENT: People get and keep employment consistent with their interest, abilities and needs.

Goal

To promote employment for individuals with disabilities.

About the Tennessee
Disability Training Network
www.disabilitytrainingtn.org

The Tennessee Disability Training Network provides a centralized service where individuals can find comprehensive information about training opportunities and resources and can contribute to an efficient, effective process for meeting training needs

The Disability Training Network sustains a mechanism for

- Collecting and organizing information about training
- Promoting and disseminating training information
- Working together to meet training needs through planning and resource development

You can use the Disability Training Network's web site to search a calendar of training events and other disability topics. That URL is www.disabilitytrainingtn.org ■

For more information, contact

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Objectives

- By the end of FY2003, develop and support employment initiatives leading to employment for at least twenty-five individuals with disabilities.
- By the end of 2004 increase to 25% the number of people served by DMRS who have real jobs.

EDUCATION AND EARLY INTERVENTION:

Students reach their educational potential and infants and young children reach their development potential.

Goal

To promote inclusion of students with disabilities in educational settings.

Objective

- By the end of FY2003, provide support and education for development of inclusion principles in the community among teachers and parents in at least five communities.

HOUSING: Adults choose where and with whom they live.

Goal

To promote homeownership for individuals with disabilities.

Objective

- By the end of FY2004, at least 150 individuals will own or rent their own homes or be living in a less restrictive situation.

CHILD CARE: Children and families benefit from a range of inclusive, flexible child care options.

Goal

To bring about specific and lasting change in child care organizations to ensure full inclusion of children with disabilities.

Objective

- By the end of FY2003, assist at least five child care programs to include children with disabilities. ■

On The Road Again

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By Jim Summerville

Never lose hope.” That’s the message from Cookeville’s Michael W. Boyd. In 1994 Mr. Boyd fell 18 feet off a roof and landed on his head.

“I don’t actually remember the fall,” he says today, “but I do remember the snap in my neck.”

The accident left him without the use of his legs. He couldn’t walk, much less drive—and for six years, he was chauffeured wherever he had to go. “Nobody appreciates freedom quite like those that have had it removed,” he recalls of those days.

But now he’s back behind the wheel of a specially adapted van, thanks to Nancy Prusik and Johnny Knight. They run a driving school called “On the Road” for people with disabilities.

“A person like Michael, with spinal cord injuries but with no visual or thinking problems, can certainly drive again,” says Ms. Prusik. “We began by testing his strength and range of motion. That told us what kind of adapted vehicle he would need.”

Mr. Boyd’s classmates at Little Creek Academy wanted to purchase him a van. So his parents got Ms. Prusik involved and referred her to the classmate in charge of the project. She piqued Mr. Boyd’s interest in driving and he accepted with great joy the opportunity to try her adapted vehicle. He drove beautifully. She secretly measured him “behind his back,” then made recommendations and got bids on behalf of his classmates. “It was a



challenge to get what color van he would like out of him,” she remembers,

“but eventually he agreed to hunter green.” He is now independent and can drive to Nashville to obtain outpatient therapy.

Ms. Prusik and Mr. Kennedy say that almost any vehicle can be adapted to meet an individual’s needs. A single lever can control both the accelerator and the brake. Pull it toward you and the car will go forward. Push it away and the car slows and stops. Steering can be simplified with the use of a knob. As Mr. Boyd puts it, “What I used to do with two hands and two feet, I now do with two hands.”

Ms. Prusik and Mr. Kennedy have also helped Shelley Eagley to drive again. Ms Eagley has a learning disability.

Ms. Prusik says, “She did not get her permit the first time, she did not get her license the first time. She is the queen of perseverance.

“I started out with teaching her to drive with hand controls because her feet were uncoordinated. After she learned basic traffic rules and laws, I switched to teaching her to drive using a left foot accelerator. Later on I was able to switch her to driving with her right foot and a spinner knob for safe efficient turns.

“Michael and Shelley just show you that almost anyone with a disability can learn to drive, if given the opportunity and some high-tech help,” says Ms. Prusik. ■

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About the Council:

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